

My name is Billie Miller and I have been working in the field of developmental disabilities since December 1976, at just about every type and level of service including a large institution, group home, as a state employee who trained people who work in day programs and group homes, and now at Family Outreach where I have been for over 29 years. At Family Outreach, we work with families and their children with developmental disabilities.

In my career, I have seen many changes, as we have tried to improve the developmental disability ^{system} and make it more responsive to the needs of the people we serve while adhering to the rules and regulations that have been injected into the system and changed over time. The manner in which the system developed in the past 40 years created two parallel systems, one for children and one ^{for} adults. Those systems developed according to the unique needs of the people they served and initially, there was an understanding that the needs of adults in congregate living situations or their own apartments were qualitatively different than the needs of children who still live with their parents and guardians. Somewhere along the way, the developmental disabilities system lost its ability to discern the elemental differences between kids and adults, between people living in group homes and children living with their parents. This shift is showing up in the Children's Waiver Services.

I would like to offer a perspective on child and family services. We provide education and support through various funding sources, each with its own guidelines and eligibility criteria. But there are some important constants to the services across all those funding sources:

- Individual Family Service Plans (IFSPs)-plans of action based on the child's needs and the family's priorities
- Home visits-necessary for a family centered, home based service
- Education-child and family focused work that addresses child skill and behavioral needs as well as family needs so that parents can become the primary intervention agents for their children
- Support-emotional support, service coordination, referrals, monitoring, revising and amending plans to adjust to a child and family's changing needs

Which brings me to the constant that is remarkable because of its inconsistency. Families change-- a little or a lot, slowly or quickly, subtly or dramatically. And when a family changes, its needs change. And, if you have a child with a disability, as a family, you have an additional level of factors that can force changes: a child is born, a grandparent dies, a son blows out a knee on the basketball court, a parent gets a job, critical health insurance is lost with the loss of a job, seizures increase, a child stops sleeping through the night, a child begins running out the door every time it is open, a child needs to see a specialist in Salt Lake City, a child won't eat anything but chicken nuggets or will eat anything he finds on the floor.

What this means is that to be effective, child and family services must be flexible and responsive, which brings me to my support of resolution, SJ27.

I was a Family Support Specialist when Children's Waiver Services (CWS) started. I served some of the first children to get what was then called SFC. The initials have changed a few times over the years along with other changes that were deliberate efforts to make CWS look more like adult services. Many

of these changes made the program less responsive to the parents and children being served. I would like to mention a few that we have experienced and how they impact services:

- Home visits, essential to a family centered, home based service are critical to the development of supportive relationships between families, children and Family Support Specialists. Travel time and costs are no longer reimbursed though they once were. The Family Support Specialists are required to have direct contacts with the parents and children each month and must work with and train the people who provide child focused training or respite in the home. CWS serves children in town and in remote areas of the state.
- Financial supports and their processes have changed. For example, budgets (also known as Individual Cost Plans) are approved and administered with a cumbersome and complex approval process for initial and amended budgets. April 29 is the last day that budget changes can be submitted for this fiscal year, yet there are 2 full months left in this fiscal year and June is a big change month because school ends and parents face the challenge of summer day care (which in itself is more problematic for parents of children with disabilities). So, families and Family Support Specialists have to do their best to anticipate any changes that might occur in the next 2 months. That might work if everything is routine, but it will be difficult if one of those unexpected family change things happens. And, for the other 10 months, proposed amendments can take weeks to gain approval, leaving families and Family Support Specialists in limbo about whether a particular service can be provided. Under the new system, it is difficult to respond quickly and effectively to unexpected changes and emergencies.
- Quality assurance processes and systems that are developed to provide oversight and protections for adults in congregate living situations serve to protect vulnerable adults. These same layers of oversight are not necessary for families who provide the oversight and protections for their own children along with many other systems that are involved in the lives of children such as extended families, schools and therapists and health care providers. And yet, this oversight is required at a cost of time and money. For example, Family Support Specialists are required to write the same types of Incident Reports for families that are required in group homes. Child and Family agencies are responsible to complete "critical investigations" for some categories of incidents reporting which can take a great deal of time to complete.

The bottom line is kids' needs are different than adult needs. And the day to day life of a family in a family home is completely different than the day to day life in a group home of adults. The study proposed by SJ27 recognizes that those differences need to be reflected in the design of children's services. I urge your support of this resolution.

Billie Miller

1012 Peosta, Helena, 59601

442-1904